

Frequency of and Risk Factors for Behavior and Emotional Problems in Siblings of Children Diagnosed with Autism Spectrum Disorder

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Master's Thesis

May 28, 2010

Drexel University

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Abstract

Research focusing on behavior and emotional problems in siblings of individuals with autism has found specific risk factors. The current study examined risk factors identified and indicated in the literature. This study relied on a theoretical model and used a large sample taken from data collected through an autism needs assessment, distributed throughout the state of Pennsylvania. The analysis provided findings indicating specific risk factors for the presence of behavior and emotional problems in sibling of children diagnosed with an autism spectrum disorder. The twelve behavior included are separated into three scales; aggression problems, intrafamily conflicts, and depression and anxiety symptoms. The risk factors shown in the results include characteristics of the child with autism, the sibling, and parent/family characteristics.

Background

Autism is classified as a pervasive developmental disorder, defined by social and communication impairments, and the presence of unusual behaviors or interests (APA, 2000).

Autism is a life-long disorder which affects not only the diagnosed individual, but the entire family system (Morgan, 1988). Family members of individuals with autism may experience particular challenges not found in family members of individuals with other psychiatric or developmental disorders (Sanders & Morgan, 1997). When considering the family members of an individual with autism, it is important to consider the siblings in addition to the parents.

Children and adolescents with autism have been reported to experience social anxiety (Kuusikko et al., 2008). Disruptive behaviors are frequently observed in this population, including aggression, self-injury, impulsive or hyperactive behaviors including tantrums, and repetitive ritualistic behaviors (Kaminsky & Dewey, 2002). These behaviors often require adaptations from their family members. Siblings may miss out on opportunities for social growth, and recreational or educational opportunities. For example if the sibling with autism cannot attend a baseball game or a holiday party, perhaps the whole family will not attend. Siblings have reported being embarrassed by behaviors exhibited by their sibling with autism (Macks & Reeve, 2007). Additionally, siblings of individuals with autism have been found to

have increased levels of stress, especially as a result of environmental stressors, such as the sibling's behaviors or the increased stress of the parent (Orsmond & Seltzer, 2009).

In addition to the direct effect an individual with autism can have on their siblings, there may also be an indirect effect because of the changes in parenting style and resources caused by the child with autism. Parents of children with autism experience higher levels of parental and marital stress than parents of typically developing children (Bagenholm & Gillber, 1991; Bebko et. al, 1987; Gray, 1998; Gray & Holden, 1992; Rivers & Stoneman, 2003; Wolf et. al, 1989; Fishman et al, 1996). As the stress level on the parent increases, the demands and expectations on other children in the family may also increase.

Contributing to the increased parental stress level is the cost of caring for a child with autism. "It can cost society about \$3.2 million to care for a person with autism over his or her lifetime" (Ganz, 2006). These costs include direct medical, such as doctor's visits and medical services, nonmedical, such as services and programs outside of the medical field, and indirect costs, such as lost productivity, including the time required by parents (Ganz, 2006).

A diagnosis of autism tends to increase the time demand on parents. Parents are expected to advocate for services for their child, pay for services, and maintain a schedule revolving around the child with autism. Services for the child with autism may take place in or out of the home. When outside the home, the parents' time may be filled with driving the child to and from service. When services are inside the home, the parent must also be present in the home and may be expected to oversight the service interactions (Ganz, 2006; Jacobson & Mulick, 2000). In turn, any demand placed on parents will affect the entire family, including the siblings of the individual with autism.

In addition to caring for a child with autism, it is important to recognize that autism is a lifelong disorder. The families of individuals with autism are affected throughout the lifespan of the individual with autism. Their parents must plan for services during childhood and adolescence, and also plan for the care the individual will receive as an adult. If the child is significantly impaired, the parent must make plans to care for the individual throughout their lifetime (Jaconson & Mulick, 2000; Ganz, 2006). This may include using monetary means to prepare for care for the individual, or plan for a sibling, often a sister, to become the primary caregiver after the parents are no longer able to care for them (Orsmond & Seltzer, 2009; Verte, Roeyers & Buysse, 2003). Either of these scenarios can affect the sibling, either directly, with the sibling planning to be a caregiver, guardian or trustee to the individual with autism, or indirectly through the loss of money or opportunities that may have been otherwise afforded the sibling.

As the demand on parent's time is increased by a child with autism, the time available to other children in the home is decreased. This can result in less attention from the parents for the nondisabled children, or limit the activities these children can participate in (Macks & Reeve, 2007; Hastings, 2003a). If a parent must spend time to take a child with autism to services, they do not have as much time to accompany other children to extracurricular or enrichment activities, or to offer them services that could address a sibling's potential medical, psychological or educational needs. Also, the nondisabled child may be too young to be left alone and must accompany the parents and sibling to autism services, depriving them of time for homework, peer relations or self-initiated recreational activities.

If an increase of stress placed on the parents has a negative effect on the parent's mood, the other children in the home will be affected by the parent's mood and attitude. Rivers and

Stoneman (2003) found that marital discord was associated with compromised sibling relationships. Additionally, the financial hardship, which can accompany a diagnosis of autism, may be a strong factor into marital discord (Ganz, 2006).

The influence of having a sibling with autism has not been well researched (Kaminsky & Dewey, 2002; Macks & Reeve, 2007). It is important to understand how siblings of individuals with autism are affected, with consideration for improving negative consequences. In addition to improving quality of life for these individuals for themselves, these siblings frequently act as the current and future caregivers, advocates, and teachers for their siblings who are diagnosed with autism. In the scant existing literature focusing on the siblings of individuals with autism, most studies have limitations including small sample sizes and lack of focus on the causes of behavior and emotional problems in siblings. Some studies draw inconsistent conclusions or do not have the power to draw firm conclusions.

In 1990, Mates claimed that siblings of individuals with autism were not at an increased risk for behavior and emotional problems, as long as they did not have specific risk factors (Mates, 1990). More recent studies failed to control for the factors which may be increasing the risk for behavior and emotional problems. (Gold, 1993; Bagenholm & Gillberg, 1991).

Two studies, Gold (1993) and Kaminsky & Dewey (2002), found different results regarding the presence of depression symptoms in siblings of children with autism. Gold found that siblings had a higher rate of depression, while Kaminsky & Dewey found that siblings of children with autism were well adjusted and had low levels of depression symptoms. However, Gold's study focused on siblings of boy's with autism, while Kaminsky & Dewey did not control for the sex of the sibling. This leads to the conclusion that results in this area have been inconsistent due to the lack of controlling for risk factors. The current study focuses on

controlling for previously identified and indicated risk factors. Even when risk factors were considered and groups were matched accordingly, studies continued to be limited by small sample sizes (Pilowsky et al., 2004; Kaminsky & Dewey, 2002).

In addition to higher parental stress, higher levels of stress and other behavioral and emotional problems have been reported in siblings of individuals with autism when compared to individuals with a non-autistic sibling (Bagenhom & Gillber, 1991; Gibbs, 1993; Hastings, 2003b; Howlin, 1988; Kaminsky & Dewey, 2002). These individuals tend to display increased levels of internalizing and externalizing behaviors (Rodrigue et al., 1993; Ross & Cuskelly, 2006).

These individuals tend to suffer from greater level of depressive and anxiety symptoms than individuals who have a sibling with no disabilities (Gold, 1993; Gray & Holden, 1992). Kaminsky & Dewey (2002) identified higher levels of loneliness and poor psychosocial adjustment in siblings of individuals with autism. Orsmond & Seltzer (2009) also identified these siblings at a higher risk for social and behavioral adjustment. Siblings of individuals with autism also performed lower on achievement and self-concept scales (Mates, 1990). Furthermore, the individuals who had a sibling with autism were reported as having more adjustment problems than individuals who had a sibling with another developmental disorder (Pilowsky et al., 2004; Roeyers & Mycke, 1995; Yirmiya et al., 2001).

Risk Factors

The existing literature on siblings of individuals with autism has identified specific risk factors for behavior and emotional problems. These risk factors include being the male sibling of an individual with autism (Macks & Reeve, 2007), having only two children in the family

(Macks & Reeve, 2007; Bagenholm & Gillber, 1991; Mulroy et al., 2008; Gamble & McHale, 1989; McHale et al., 1986; Kaminsky & Dewey, 2002; Pilowsky et al., 2004), being older than the sibling with autism (Macks & Reeve, 2007; Hastings, 2003a; Mates, 1990; Gamble, 1989; Howlin, 1988; Mulroy et al., 2008), and low socioeconomic status (Macks & Reeve, 2007; Mulroy et al., 2008; Deater-Deckard et al., 1998).

Another potential risk factor that has been hypothesized is the presence of more severe autism (Gold, 1993). However, there is minimal support for severity acting as a risk factor. When comparing siblings of children with autism to those with Down Syndrome, Kaminsky & Dewey found no difference according to severity (2002). This inconsistency may be due to poor operational definition of “severity.”

Other identified risk factors which are important to consider when looking at families of individuals with autism include being siblings of the same sex (Dunn & Kendrick, 1982) and having an adverse family structure such as single parent homes, presence of stressful life event, parental stress, and social isolation (Deater-Deckard et al., 1998). These factors are especially important in the context of siblings of individuals with autism due to the disruptive behaviors commonly exhibited by a child with autism.

Due to the sparse literature available about siblings of individuals with autism, a more extensive look at siblings of individuals with other conditions was conducted. In 1981 Breslau found that in families who had a child with a developmental disorder, if the children were close in age and were both boys, they were at risk for behavior and emotional problems. In studies in 1992, Cuskelly & Dadds, and 1993, Cuskelly & Gunn, found that sisters of an individual with Down Syndrome were at risk for behavior and emotional problems.

In a study looking at the effects childhood cancer has on the siblings of a sick individual it was found that degree of family disruption was a significant risk factor for behavior and emotional problems in healthy siblings (Sloper & While, 1996). This finding is particularly important to a study involving siblings of individuals with autism due to the unpredictable nature of autism and the amount of family disruption often found in these families.

Study Design

The current study examined the characteristics of the various members of a family unit, in which at least one child has a diagnosis of autism spectrum disorder. The study attempts to organize and show how these characteristics can act as risk factors for behavior and emotional problems in the sibling of an individual with autism.

This study focuses on risk factors for behavior and emotional problems in siblings, relies on a theoretical model to conceptually guide how the factors affect the sibling, and takes advantage of a large sample. The model used in this study is based on the social ecology of pediatric illness from Power, DuPaul, Shapiro, and Kazak (Handbook of Pediatric Psychology, 2003). The theoretical model (See Figure 1) places the sibling as the central factor in the model to show how the individual with autism and the parents both have an effect on that sibling. Specifically, the characteristics of other family members affect the central child, and needs of the individual with autism, specifically a change in parental workforce and accessing services, can affect the parents and in turn, affect the central child.

Methods

Dependent Variables

The dependent variables included in the study come from twelve questions about a sibling's behavior and emotional problems (See Appendix 2). These variables were combined into three subscales: aggressive behaviors, intrafamily conflicts, and depressed and anxious behaviors (See Figure 2).

The aggressive behavior component included being physically aggressive, being verbally aggressive, had conflicts with authority figures, and conflicts with peers. The intrafamily component included conflicts with parents, conflicts with sibling with ASD, and complained about sibling with ASD. The depressed and anxious component included seemed depressed, seemed anxious, complained that no one loved or cared about him/her, threatened suicidal behaviors, and exhibited suicidal or self injurious behaviors.

Independent Variables

The independent variables examined in this study include characteristics of the sibling, characteristics of the child with autism, and characteristics of the parent or family system as a whole. (Figure 2; for a complete list of questions see Appendix 1). The characteristics of the sibling which act as independent variables include age difference with the child with autism, birth order, and being a male sibling. The variables of age difference and birth order are combined into one variable. Younger siblings are shown with negative age difference, while older siblings have a positive age difference. The characteristics of the child with autism which act as independent variables include functioning ability, having a more severe diagnosis of autism, specifically autistic disorder, compared to PDD-NOS (pervasive developmental disorder, not otherwise specified) and asperger's disorder, behavior problems, and number of services currently being accessed. The parental or family characteristics which act as independent

variables in this study include being/having a single parent, lower family income, the number of children in the family, an increase in workforce participation, and difference in age and sex of the two siblings.

Hypotheses

We hypothesize that an individual with autism can have a direct effect on their sibling by their own behaviors or they can have an indirect effect with the parent acting as a moderator. Furthermore, there are characteristics of the members of the family which can act as risk factors for behavior and emotional problems in the sibling of the individual with autism. The specific characteristics of an individual who has a sibling with autism include being the older sibling of a child with autism, being male, being the opposite sex from the sibling with autism, and being close in age to the sibling with autism. The characteristics of the sibling with autism include a more severe diagnosis of autism and behavior indicating poorer functioning. Finally, characteristics of the parents or family as a whole include higher parental workforce participation, being a single parent, and having low socioeconomic status. These factors are likely to increase aggressive behaviors, intrafamily conflicts, and depression and anxiety behaviors in the sibling of the individual with autism.

Participants

The study included 1,327 surveys completed by parents or primary caregiver of individuals with autism, currently living in the state of Pennsylvania. All of the participants had two or more children, at least one of whom had an autism spectrum disorder diagnosis. The participant's oldest child with ASD was currently in elementary, middle, or high school. The

sibling included in this study was the sibling closest in age to the child with ASD. The age of siblings evaluated in this study ranged from 4 years to 26 years. The mean age was 12 years; 9 months, and the SD was 4 years; 11 months. The participants were only included if the sibling did not have a current ASD diagnosis. This was done to attempt to control for ASD symptoms mimicking the behavior and emotional problems being studied.

Measure

The data set was collected from a service needs assessment for people with autism in Pennsylvania (2009). There were five versions of the survey, specified by age of the child with autism. These versions included children who are currently in Elementary School or Middle or High School.

Procedure

In 2009 a letter was sent to 30,000 individuals throughout the commonwealth of Pennsylvania describing the needs assessment and inviting individuals to participate. The individuals who received this letter were Medicaid-enrolled individuals with an autism diagnosis in 1999, 2004, and 2009. After receiving the letter, individuals were able to access the assessment online through the use of REDCap, an online survey instrument, or request a paper form. The assessment was available in both English and Spanish.

The assessment was completed by the parent or primary caregiver of an individual with ASD. The parent was instructed to complete the assessment for their oldest child with ASD. For questions specific to siblings, the parents were instructed to answer the questions in regard to the sibling closest in age to the child they answered the majority of the assessment for.

The data set for the current study was abstracted from the study conducted in 2009. This data set is de-identified and permission for use of this data set was granted from The Bureau of Autism Services, Pennsylvania Dept of Welfare, the owners of the original data set. The data set used for the current study only included surveys from Elementary School and Middle and High School assessments.

Analysis

Frequencies and means were calculated for all variables of interest. The distribution of each of the items included in the dependent variables was examined and all were relatively normal. Strong correlations among the items were found and factor analysis was conducted to determine possible subscales.

We conducted a Principal Component Analysis for the extraction method and used Varimax with Kaiser Normalization to determine the three subscales which were used. After determining the importance of each item to scale we created a total scale (total sibling problems), which included the twelve items of dependent variables, and three subscales (aggression problems, intrafamily conflicts, and depression and anxiety symptoms). The assignment of the items into each of these subscales was also theoretically supported in that the items: physical aggression, verbal aggression, conflicts with peers, and conflicts with authority figures (aggression problems); conflicts with parents, conflicts with sibling with ASD, and complained about sibling with ASD (intrafamily conflicts); and depression symptoms, anxiety symptoms, threatened suicidal behaviors, exhibited self-harming behaviors, and complained about sibling with ASD (depression and anxiety symptoms) logically relates to the other items in the subscale.

A correlation analysis was conducted on the problem behaviors and abilities of the child with ASD (Figure 2). Strong correlation was shown in all these variables, so we combined these factors into one total ability scale by reversing the problem behaviors, for example if a child is rated as displaying depression symptoms they would receive a score of zero towards their total ability score. On the other hand, if no depression problems are reported the child would be given a score of one on the ability scale. All the factors were added together to compute one total ability score. A total score was computed for number of services the child with ASD is currently receiving, birth order was determined by the positive or negative age difference between siblings, an increase in parent workforce was determined on the basis of one or more parent reporting an increase, and number of children was categorized as 2 or more than 2 based on previous research indicating a difference between these categories, rather than a continuous trend. Several factors including age of sibling, birth order, total ability, number of services receiving, number of children, and age difference between siblings were divided into theoretically designed categories.

Linear regression was conducted comparing the potential risk factors to the total scale and subscales. The assumption of homogeneity of variance was not met as determined by Levene Statistic. We then applied a linear regression using Heteroskedasticity-Robust Inference by using a Heteroskedasticity-Consistence Standard Error Estimator as described and supported by Hayes & Cai (2007).

Results

Table 1 provides the mean score on each dependent variable scale or subscale for all variables included in the study. Statistically significant difference in means was found on the

total problem scale in age of sibling ($F(5,1321)=4.54, p< .001$) with more problems when the child's age is 12-15 years. The ability score of the child with ASD ($F(3, 1323)=19.90, p< .001$) showed more problems in lower ability score. When looking at the autism diagnosis ($F(2, 1324)=12.89, p< .001$) more problems were seen in aspergers. When there is only one parent in the home there are more total problems ($F(1, 1325)= 9.37, p= .002$). Lower family income ($F(5, 1321)=10.76, p< .001$) indicated more problems. Having more than two children showed more problems when compared to only two children in the family ($F(1, 1325)=4.75, p= .030$). The age difference between siblings ($F(10, 1316) =2.65, p= .003$) showed more problems when siblings were younger and closer in age.

Significant difference in means was found on the aggression scale in each of the following variables. Males siblings indicate more problems ($F(1, 1325)=15.5, p= .002$). There were more problems when the ability score of the child with ASD was lower ($F(3, 1323)=12.29, p<.001$). The autism diagnosis ($F(2, 1324)=6.38, p= .002$) showed more problems in aspergers. More problems were found when there was only one parent in the home ($F(1, 1325)=16.76, p< .001$). The family income ($F(5, 1321) =13.37, p< .001$) showed more problems when there was lower family income. The number of children in the family ($F(1, 1325)=8.94, p= .003$) showed more problems when there were more than 2 children in home. The age difference between siblings ($F(10, 1316)=3.19, p<.001$) showed more problems when siblings are closer in age. The sex convergence between siblings ($F(1, 1325)=6.92, p= .009$) showed more problems in siblings of the same sex.

Significant difference in means was found on the intrafamily conflict scale in age of the sibling ($F(5, 1321)=7.47, p< .001$) with more problems at 12-15 years of age. A lower score on the ability scale of the child with ASD indicated more intrafamily problems ($F(3, 1323) =21.26,$

$p < .001$). More intrafamily conflicts were seen when the child with ASD had a specific diagnosis of aspergers ($F(2, 1324) = 28.95, p < .001$). Family income between \$20,000 and \$39,999 showed more problems ($F(5, 1321) = 3.34, p = .005$). When siblings were approximately three to five years older than their sibling there were a higher number of intrafamily conflicts ($F(10, 1316) = 2.65, p = .003$).

Significant difference in means was found on the depression/anxiety scale in age of the sibling ($F(5, 1321) = 5.64, p < .001$) with more problems around 12-15 years. Lower scores on the ability scale of the child with ASD indicated more depression and anxiety problems ($F(3, 1323) = 9.82, p < .001$). More depression/anxiety problems were found when there was only one parent in the home ($F(1, 1325) = 5.90, p = .015$). Lower family income showed more depression/anxiety problems ($F(5, 1321) = 8.52, p < .001$). More problems were found when the siblings were younger and within 19 months of age ($F(10, 1316) = 1.86, p = .047$).

Table 2 provides the results of the linear regression predicting number of problems on the total scale and each of the subscales. The total number of problems ($F(34, 1292) = 5.74, p < .001$) is greatest in children aged 12-15 years in age, children whose sibling has a lower ability score and less severe ASD diagnosis, children whose family income is lower, and younger siblings who are within 19 months of age to their sibling with ASD. The number of problems on the aggression subscale ($F(34, 1292) = 4.42, p < .001$) is greatest in children aged 7-12 years, male siblings, children whose sibling has a lower ability score and less severe ASD diagnosis, children whose family income is lower, and younger siblings who are within 19 months of age to their sibling with ASD. The number of problems on the intrafamily conflicts subscale ($F(34, 1292) = 7.07, p < .001$) is greatest in children aged 12-15 years, children whose sibling has a lower ability score and less severe ASD diagnosis, children whose family income is lower, but not the

lowest score of under \$20,000/year, children whose parents have increased their workforce participation, and siblings who are approximately three to five years older than their sibling with ASD. The number of problems on the depression/anxiety subscale ($F(34, 1292)=3.89, p< .001$) is greatest in children aged 12 to 15 years of age, children whose sibling with ASD has a lower ability score and less severe ASD diagnosis, children whose family income is lower, and younger siblings who are within 19 months of age of their sibling with ASD.

Table 1: mean problem scores for siblings of children with autism					
	N= 1327	Total Problems	Aggression	Intrafamily	Depress/ Anxiety
Age of Sibling	1327	18.3 (p< .001)	5.6 (p=.351)	6.0 (p< .001)	6.7 (p< .001)
<=7 years	180	17.5	5.7	5.7	6.1
7:1-9 years	148	18.5	5.7	6.2	6.6
9:1-12 years	283	18.6	5.7	6.1	6.7
12:1-15 years	289	18.9	5.6	6.3	7.0
15:1-18 years	211	18.7	5.7	6.2	6.8
18:1 years and older	216	17.3	5.4	5.4	6.5
Sex of Sibling	1327	18.3 (p=.334)	5.6 (p=.002)	6.0 (p=.702)	6.7 (p=.279)
Male	594	18.5	5.8	6.0	6.6
Female	733	18.2	5.5	6.0	6.7
Total Ability	1327	18.3 (p< .001)	5.6 (p< .001)	6.0 (p< .001)	6.7 (p< .001)
Up to 6	253	19.2	5.9	6.2	7.0
7	223	19.8	6.1	6.7	7.0
8	356	18.4	5.6	6.2	6.6
9	495	17.1	5.3	5.5	6.4
Autism Diagnosis	1327	18.3 (p< .001)	5.6 (p=.002)	6.0 (p< .001)	6.7 (p=.350)
Autism	452	17.7	5.4	5.6	6.6
PDD-NOS	503	18.1	5.6	5.9	6.6
Aspergers	372	19.3	5.9	6.6	6.8
# of services	1327	18.3 (p=.363)	5.6 (p=.706)	6.0 (p=.871)	6.7 (p=.087)
< 3 services	280	17.9	5.5	5.9	6.5
4-5 services	298	18.4	5.7	6.1	6.7
6-7 services	345	18.4	5.6	6.0	6.7
8 services	146	18.1	5.6	6.0	6.6
9+ services	258	18.7	5.8	6.1	6.9
# of parents in home	1327	18.3 (p=.002)	5.6 (p< .001)	6.0 (p=.232)	6.7 (p=.015)
1 parent	270	19.1	6.1	6.1	6.9
2 parents	1057	18.1	5.5	6.0	6.6
Family Income	1327	18.3 (p< .001)	5.6 (p< .001)	6.0 (p=.005)	6.7 (p< .001)
Under 20	145	20.0	6.4	6.3	7.3
20-39,999	239	19.0	6.0	6.1	6.9
40-59,999	246	18.9	5.8	6.3	6.9
60-79,999	222	17.6	5.4	5.8	6.3
80-99,999	169	18.2	5.5	6.0	6.7
100 or more	306	17.1	5.1	5.7	6.3
Number of Children	1327	18.3 (p=.030)	5.6 (p=.003)	6.0 (p=.176)	6.7 (p=.264)
2 children	706	18.0	5.5	5.9	6.6
More than 2 children	621	18.6	5.8	6.1	6.7
Parent workforce	1327	18.3 (p=.290)	5.6 (p=.744)	6.0 (p=.032)	6.7 (p=.440)
Increase in workforce	82	18.9	5.6	6.5	6.8
No increase in workforce	1245	18.3	5.6	6.0	6.7
Age Difference btw Sibs	1327	18.3 (p=.003)	5.6 (p< .001)	6.0 (p=.003)	6.7 (p=.047)
-59 months and more	63	17.0	5.4	5.4	6.1
-38-58 months	143	18.1	5.6	6.0	6.4
-26-37 months	138	18.6	5.8	6.1	6.6
-20-25 months	107	17.9	5.3	6.2	6.4
-1-19 months	96	19.8	6.2	6.5	7.1
0 months	51	19.5	6.3	6.2	7.0
1-19 months	143	18.4	5.7	5.9	6.8
20-25 months	139	18.0	5.3	6.0	6.7
26-37 months	144	17.5	5.2	5.8	6.5

38-58 months	124	19.1	5.8	6.5	6.8
59 months and more	179	18.2	5.7	5.7	6.8
Sex Convergence	1327	18.3 (p=.403)	5.6 (p=.009)	6.0 (p=.920)	6.7 (p=.529)
Same sex	713	18.2	5.5	6.0	6.7
Different sex	614	18.4	5.8	6.0	6.6

Table 2: Heteroskedasticity-Consistent Regression Results					
	N= 1327	Total Problems	Aggression	Intrafamily	Depress/ Anxiety
Age of Sibling					
<=7 years		.6 (p=.304)	.5 (p=.043)	.4 (p=.091)	-.3 (p=.212)
7:1-9 years		1.4 (p=.021)	.4 (p=.059)	.9 (p< .001)	.1 (p=.762)
9:1-12 years		1.3 (p=.008)	.4 (p=.051)	.7 (p< .001)	.2 (p=.275)
12:1-15 years		1.9 (p<.001)	.4 (p=.036)	.9 (p< .001)	.5 (p=.005)
15:1-18 years		1.4(p=.002)	.4 (p=.037)	.8 (p< .001)	.3 (p=.155)
18:1 years and older		REFERENCE			
Sex of Sibling					
Male		.3 (p=.334)	.3 (p=.031)	.2 (p=.265)	-.1 (p=.342)
Female		REFERENCE			
Total Ability					
Up to 6		2.0 (p<.001)	.6 (p< .001)	.9 (p< .001)	.6 (p<.001)
7		2.2 (p<.001)	.6 (p< .001)	1.1 (p< .001)	.5 (p=.003)
8		1.1 (p<.001)	.3 (p=.019)	.6 (p< .001)	.2 (p=.157)
9		REFERENCE			
Autism Diagnosis					
Autism		REFERENCE			
PDD-NOS		.9 (p=.007	.3 (p=.041)	.5 (p< .001)	.2 (p=.227)
Aspergers		2.2 (p<.001)	.6 (p< .001)	1.2 (p< .001)	.4 (p=.011)
# of services					
< 3 services		REFERENCE			
4-5 services		.2 (p=.569)	.1(p=.684)	.0 (p=.924)	.1 (p=.343)
6-7 services		.5 (p=.196)	.1 (p=.466)	.1 (p=.547)	.3 (p=.058)
8 services		.0 (p=.928)	.0 (p=.998)	.0 (p=.915)	.0 (p=.905)
9+ services		.8 (p=.068)	.3 (p=.141)	.2 (p=.251)	.3 (p=.057)
# of parents in home					
1 parent		-.1 (p=.844)	.0 (p=.924)	.0 (p=.837)	-.1 (p=.694)
2 parents		REFERENCE			
Family Income					
Under 20		2.7 (p<.001)	1.2 (p< .001)	.5 (p=.045)	1.0 (p<.001)
20-39,999		1.9 (p<.001)	.9 (p< .001)	.4 (p=.039)	.6 (p<.001)
40-59,999		1.8 (p<.001)	.7 (p< .001)	.5 (p< .001)	.6 (p<.001)
60-79,999		.4 (p=.288)	.2 (p=.094)	.1 (p=.635)	.1 (p=.628)
80-99,999		1.1 (p=.008)	.4 (p=.008)	.2 (p=.262)	.5 (p=.004)
100 or more		REFERENCE			
Number of Children					
2 children		REFERENCE			
More than 2 children		.1 (p=.775)	.1 (p=.299)	.0 (p=.919)	.0 (p=.828)
Parent workforce					
Increase in workforce		.4 (p=.405)	-.1 (p=.584)	.4 (p=.041)	.1 (p=.571)
No increase in workforce		REFERENCE			
Age Difference btw Sibs					

Hemming- Sibling Risk Factors 19

-59 months and more		REFERENCE			
-38-58 months		1.1 (p=.058)	.3(p=.251)	.5 (p=.035)	.3 (p=.237)
-26-37 months		1.8 (p=.005)	.5 (p=.049)	.7 (p=.008)	.5 (p=.043)
-20-25 months		1.2(p=.055)	.1 (p=.798)	.8 (p=.009)	.3 (p=.154)
-1-19 months		2.7(p< .001)	.9 (p=.006)	1.0 (p=.001)	.9 (p=.002)
0 months		2.0 (p=.019)	.8 (p=.022)	.5 (p=.155)	.6 (p=.057)
1-19 months		1.7 (p=.010)	.5 (p=.114)	.6 (p=.028)	.6 (p=.021)
20-25 months		1.4 (p=.031)	.2 (p=.386)	.7 (p=.011)	.4 (p=.097)
26-37 months		1.0 (p=.120)	.1 (p=.639)	.6 (p=.038)	.3 (p=.252)
38-58 months		2.3 (p=.002)	.6 (p=.039)	1.1 (p< .001)	.5 (p=.080)
59 months and more		1.5 (p=.028)	.5 (p=.093)	.5 (p=.086)	.5 (p=.075)
Sex Convergence					
Same sex		REFERNCE			
Different sex		.0 (p=.922)	.1 (p=.665)	-.1 (p=.606)	.0 (p=.745)

Discussion

As hypothesized, this study found that children who were close in age, specifically within 19 months, to a sibling with autism tend to display more of all the behavior and emotional problems included in this study. Furthermore, when looking at birth order, previous research has focused on whether an individual is older or younger than their sibling with autism (Macks & Reeve, 2007). This study included twin siblings, and found, consistent with small age difference, that twin siblings tend to display more problems than either older or younger siblings. This is consistent with literature indicating a smaller age gap may act as a risk factor (Breslau, 1981).

When siblings are closer in age they tend to have the same or similar peer group. If these two siblings have the same peer group it is likely that the sibling will display more problems as they may spend more time with that child, or they are compared to that child, either by peers, teachers, or even parents. Siblings often report feelings of embarrassment, which would be increased by a joint social environment (Mack & Reeve, 2007).

However, when looking at older and younger siblings, this study finds differing results from the literature and our hypothesis, in that children who are the younger siblings tend to display more problems than the older siblings (Macks & Reeve, 2007). Specifically, younger siblings who were close in age tend to display the highest number of behavior problems. However, when looking at intrafamily conflicts, older siblings who were roughly three to five years older than the child with autism displayed the most problems. Previous research has suggested that siblings of children with autism are sometimes given extra responsibilities, including caregiver responsibilities (Orsmond & Seltzer, 2009; Verte, Roeyers & Buysse, 2003; Lobato & Kao, 2002). Research does not indicate a specific age of siblings being affected, so additional research should focus on specific age groups to determine if there is a particular age

affected by these extra responsibilities. This study shows a higher number of intrafamily conflicts when siblings are roughly 3-5 years older, so it would be important to measure additional responsibilities by the age of the sibling.

Similarly, the specific age of the sibling is important to consider when looking at behavior and emotional problems. The age range which displayed the most behavior problems, except aggression, was 12-15 years old. It is important to recognize that this trend may be true of children whose siblings are all typically developing. Additionally, the most aggression problems were seen in ages 7-12. This may also be a trend in typical developing populations. This study attempts to build on previous literature, so rather than looking at problems in this population compared to a control group, the study focuses on the siblings of children with autism and what factors increase the risk for problems in these individuals.

When looking at the sex of the sibling, significance was only found in the total number of aggression problems. In this subscale males displayed more problems. Owing to the lack of control group in this study, we are unable to determine whether being the brother of an individual with autism increases the number of aggressive problems, or if this is simply a trend for boys, regardless of sibling diagnoses (Breslau, 1981). However, as already noted, this study was not designed to compare siblings of children with autism to siblings of typically developing children. While this trend may be seen in a typical population, this study identifies being a male sibling as a risk factor for this population.

We attempted to measure the severity of autism through a series of problem behaviors and abilities in the child with ASD and the specific ASD diagnosis (Schwartz, 2003). We rated the severity of diagnosis with autistic disorder as the most severe, Pervasive Developmental Disorder Not Otherwise Specified next, and Aspergers Disorder the least severe. Also, we

equated higher ability score with less severe. However, the results indicate that there may be an interaction between these two factors. We found that the more severe the diagnosis, the less problems were displayed by the sibling. This can possibly be explained by the fact that ASD is largely an “invisible” disorder, in that the diagnosis is not usually accompanied by physical features. This is especially true in the less severe aspergers disorder. It is possible that sibling’s peers are less likely to recognize a true problem in these less severe children and judge the child more harshly. However, when a child is more severe and the child is nonverbal or the ASD is accompanied by mental retardation, odd behaviors displayed by this child will be judged less harshly and accepted by others. Yet our findings indicate that on the ability scale, the less able the child with ASD, the more problems displayed by the sibling. This may be explained by ability across the ASD diagnosis, in that more problems are displayed by siblings of individuals with aspergers who are less able, rather than individuals with aspergers who are more able. A child may display more problems if they are required to provide more help to their less able sibling. It may be important to separate out the problem behaviors of the child with ASD to determine if particular problems, such as running away, lead to more problems in the sibling (Macks & Reeve).

As expected the study found that the lower the family income, the more problems were displayed by the sibling. However, while this trend was found in the intrafamily conflicts subscale, the lowest income category did not show the highest number of problems. This could possibly explained by children being less likely to cause problems in the home situation when the family was less stable. While this is interesting and requires further investigation, these children do display problem behaviors outside the home, so it is important to remember that lower family income does act as a risk factor.

The measure in this study asked parents if they increased their workforce participation in response to the ASD diagnosis. The findings of this study show that when there was an increase in workforce there was also an increase in the sibling's intrafamily conflicts. This may be explained by siblings being given more responsibility for the child with ASD. The intrafamily conflicts subscale included conflicts with parents, conflicts with sibling with ASD, and complained about sibling with ASD. If the sibling is given more responsibility and expectation it is possible that they would be more likely to display these behaviors, rather than an increase in problems outside of the home (Cuskelly & Dadds, 1992; Cuskelly & Gunn, 1993).

The majority of literature in this field suggests that having a family with only two children acts as a risk factor for more behavior problems (Macks & Reeve, 2007; Kaminsky & Dewey, 2002; Mates, 1990). This study did not find significance in this variable. The aggression scale used in this study included conflicts with peers and authority figures. As already discussed, smaller age difference may be a risk factor due to a similar peer group. The measure used in this study asked parents to answer about the sibling closest in age to the child with ASD. In this sample, when there were only two children in the family it is possible that the age difference was larger, reducing the chance that the siblings share a peer group. While this is only a possible explanation further investigation into interactions between age difference and number of siblings would be important for the aggression subscale.

Sex convergence and sex of the sibling were included in this study, yet findings were not significant. This may be explained by greater number of males diagnosed with ASDs compared to females (APA, 2000). 82% of the children with ASD included in this study were male, which indicates that when the siblings were also male they tended to display more problems. This is consistent with the previously discussed variable of sex of the sibling- males tend to display a

greater total number of problems. Due to the small number of females who had a sister with ASD (10%), we cannot determine whether being the same sex as your sibling is actually a risk factor, or if simply being a male sibling of a largely male population is the true risk factor.

Limitations

This study contained limitations that must be considered. This study used a new measure which has not been studied or validated. The measure was based entirely on parental report of the behavior exhibited by their child. The problem items included on the study may only cover some of the potential problems that may be exhibited in these children. Parental report could also be limiting this study in that the parents may be displaying differential parenting. These parents may be expecting more of their child who does not have ASD and as such are rating the child with more problems. Research indicates that parents tend to rate their child more negatively than the child rates themselves (Macks & Reeve, 2007).

Another limitation lies in an understanding of the broader autism phenotype. This study looks at the siblings of a child with ASD, but that child may also be displaying features of autism. As discussed in the methods section, this study only included siblings who did not have an ASD diagnosis. This distinction was included to attempt to control for autistic traits which may be rated as the behavior and emotional problems included in this study. Some of the behaviors acting as dependent variables, specifically conflicts with peers, conflicts with authority figures, self-harming behavior, and aggressive behaviors may actually be autistic traits, rather than traits that result from having a sibling with ASD. While we did exclude siblings who also had an ASD diagnosis, these siblings may have autistic traits without an official diagnosis of autism.

Implications

This study provides several implications. Many of the previously identified risk factors were supported, or when an inconsistency occurred in findings, this study's large and wide population may provide a guide to lead future research.

This study provides evidence for a variety of risk factors for siblings of individuals with ASD. These findings indicate that there is a definite need for recognizing these risk factors and working with the individuals who fall into these categories to improve their quality of life.

Overall, the study supports the findings that the less stable a home environment, such as lower family income and only one parent in the home, lead to more behavior problems in the child. The study also supports the idea that the closer in age (and possibly peer groups) the siblings are to each other, the greater the risk is for behavior and emotional problems in the sibling. This is indicated by the age difference and sex convergence (although the sex convergence may just be consistent with males having more behavior problems). More investigation into the severity of autism is important to determine true risk factor for sibling problems. A better measure of severity is required rather than simply relying on a parents rating on a restricted set of items.

A great deal of research needs to be conducted and continued in this area to determine the specific risk factors and the specific problems exhibited by the siblings of children with ASD. It is important to be able to recognize these risk factors and problems to be able to potentially provide services to these children who are so obviously affected, and overall improve their quality of life.

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Figure 1

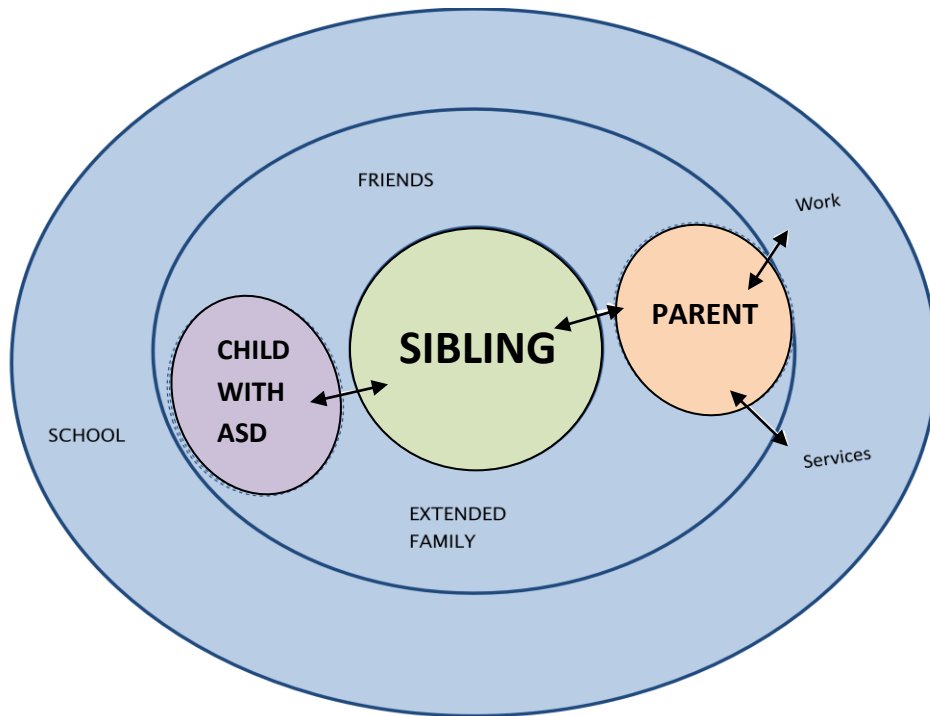


Figure 2

TOTAL PROBLEMS	AGGRESSION	INTRA-FAMILY	DEPRESSION/ ANXIETY
	Physical aggression Verbal aggression Conflicts with authority figures Conflicts with peers	Complained about sibling with ASD Conflicts with parents Conflicts with sibling with ASD	Seemed anxious Seemed depressed Exhibited self-harming behaviors Threatened suicidal behaviors Complained no one loved/cared about them

CHARACTERISTICS OF SIBLING	CHARACTERISTICS OF CHILD WITH ASD	CHARACTERISTICS OF PARENT/FAMILY
Age of sibling Birth Order <i>Younger</i> <i>Older</i> <i>Same Age</i> Sex of sibling	Total ability scale <i>toileting</i> <i>eloping</i> <i>sleep</i> <i>self-injurious</i> <i>aggressive</i> <i>feeding self</i> <i>dressing self</i> <i>requesting things</i> <i>indicating sick or hurt</i> Autism Diagnosis <i>autism</i> <i>asperger's</i> <i>PDD-NOS</i> Total # of services currently being accessed	Number of parents in home Family income Number of children <i>Two children</i> <i>More than two children</i> Increase in parent workforce participation Age difference between siblings Sex convergence of siblings

Appendix 1

Which of the following best describes your current marital status?

- ☐ Married to/Living with child's other parent
- ☐ Married to/Living with person other than child's parent
- ☐ Never been married
- ☐ Separated/Divorced
- ☐ Widowed

Which of the following is closest to your annual household income?

- ☐ Under \$20,000
- ☐ \$20,000-\$39,999
- ☐ \$40,000-\$59,999
- ☐ \$60,000-\$79,999
- ☐ \$80,000-\$99,999
- ☐ \$100,000 and above

What is the sex of your child?

- ☐ Male
- ☐ Female

How old is your child? _____ years _____ months

How many siblings does he/she have? _____

What is your child's primary diagnosis?

- ☐ Asperger's Disorder
- ☐ Pervasive Developmental Disorder (PDD/NOS)
- ☐ Autistic Disorder/Autism

In what ways (if any) has your child's autism affected your family's workforce participation?
(Check all that apply)

	Me	My Partner
Increased work hours	<input type="checkbox"/>	<input type="checkbox"/>

Is your child capable of the following activities?

	Independently	With help	Not capable
a. Toileting	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
b. Feeding Self	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
c. Dressing Self	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
d. Requesting things he/she needs	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
e. Requesting things he/she wants	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>

➔ Please answer the following questions in regard to the sibling closest in age to the child with autism, even if this sibling does not have autism.

How old is this sibling? _____ years _____ months

What is their sex?

- ☐ Male
☐ Female

Based on this sibling's behavior in the last week, how many times has this child exhibit the following behaviors?

"This child ..."

	1-4 times	5-9 times	10-14 times	15 or more times
Was physically aggressive	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Was verbally aggressive	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Acted anxious	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Acted depressed	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Made suicidal threats/comments	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Made suicidal/self-harming behaviors	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Complained that no one loves/cares about him/her	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Complained about their sibling with autism	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Had conflicts with parents	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Had conflicts with their sibling with autism	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Has been in trouble with law enforcement	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>

Please tell us about your child's service needs:

	My child is receiving	My child is receiving, but needs more	My child is receiving, but does not need	My child is not receiving, but needs	My child is not receiving and does not need
a. Mental Health Counseling	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
b. Speech/Language Therapy	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
c. Occupational Therapy	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
d. Physical Therapy	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
e. Social Skills Training	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
f. One-to-one Support	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
g. Mobile Therapy	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
h. Case Management	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
i. Neurology Services	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
j. Medication Management	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
k. Summer Camp	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
l. Summer School	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
m. Sexual Health Education	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
n. Transitional Planning	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
o. Vocational Training	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
p. Support Groups	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
q. Career Counseling	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
r. Academic Tutoring	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
s. Drug and Alcohol Counseling	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
t. Relationship Counseling	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
u. Supported Employment	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>

